# Analysis and comment

### Information technology

## Keeping the NHS electronic spine on track

Michael Cross

The NHS's "digital nervous system" is going through a jittery phase. Its next test will be its acceptance by the public

This is the second of two articles examining the NHS strategy on information technology

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This summer every household in England should receive a leaflet explaining the NHS's plan to make their health records accessible electronically. The new care records service will enable the computerised booking of appointments (based on patients' choice), electronic prescribing, the automatic transfer of complete records between general practitioners when a patient moves, as well as providing instant medical data when needed for emergency care.

Looking further ahead, the records service will create a new medical evidence base, consisting of accurate data about consistently identified individual patients, collected across health and social care. Among the users of this resource will be patients themselves, who will be able to view their records over the internet. In short, the care records service will transform the purpose of the medical record from a record of information generated by health professionals primarily for their own reference<sup>1</sup> into a shared resource produced and used by all concerned with the process of care.

#### **Progress**

Opinion polls suggest that most medical professionals support the goal of an electronic record but have concerns about the NHS in England's strategy for building it. Many concerns arise from the national scale and mandatory nature of the national programme. This year the programme, run by a Department of Health agency called NHS Connecting for Health through private contractors, begins its main deployment phase.

The government says that the care records service will be fully installed in the NHS by 2007, with health and social care information systems integrated by 2010. Liam Byrne, parliamentary under secretary of state for care services, spoke last month of "commendable progress" towards this aim. Achievements include the installation of a new broadband computer network, connected to 98% of general practices, as well as essential components of the care records service "spine."

The care records service will create electronic health records by combining central data about



patients, including their identifying characteristics (the personal demographics service), administrative records, and important health alerts such as allergies, with summaries of care episodes drawn from local institution-based electronic patient records and, eventually, social care case files.

The system making this model possible is the care records service spine. It shares a metaphor with, and puts into practice, Microsoft chairman Bill Gates's vision of a "digital nervous system" connecting disparate healthcare databases. The production version of the spine, run by BT under a contract worth £620m (€904m; \$1077m), went live in January. It is currently carrying demographic data to support "choose and book," a system which allows patients to choose where their general practitioner refers them for secondary care, as well as some electronic prescriptions and whole patient records when patients transfer between general practices—so far, only if they use the same practice system. From August, if all goes well, summaries of clinical records will begin to be loaded on the spine.

#### Spine problems

Despite the minister's comments, progress has not been smooth. Last December an upgrade to the software in the spine's demographics service resulted in what Connecting for Health described as "intermittent interruptions to the live service." This prevented doctors having access to the choose and book service and electronic prescribing. Connecting for Health said the software upgrade was a one-off event, the most complex expected to be needed in the spine's development. A statement said, "It would be naive to expect that, in an undertaking of this scale, despite constant attention to risk management, something will not go as planned."

The spine's problems arose at least partly because the demographics software turned out to be incompatible with one version of a general practice system, which generated a huge number of spurious messages, swamping the network. Such vulnerability to one piece of software, out of hundreds of separate packages in use in the NHS, illustrates why the programme attaches great importance to standardising information technology, one of the original overarching goals. However, this drive for standardisation is the source of much unhappiness about the programme's current phase.

Implementing the care records service involves replacing existing software in NHS organisations with "spine compliant" systems supplied under centrally funded arrangements by local service providers, each responsible for about one fifth of England. (One contractor, Accenture, has two neighbouring areas.) Installing the new system requires hospitals and other NHS organisations to upgrade their information technology hardware and networks, transfer data from existing systems, and train staff. The process is disruptive and resource consuming. Migrating data is particularly tricky because individual hospitals and departments have devised individual ways of entering information that may not map directly to available fields on the new screens.

#### **Delays**

The problem with this phase of the national programme is that in many cases NHS staff are being asked to put this effort into systems which, in the short term at least, represent a backward step.<sup>5</sup> This is because new software ordered through the programme has been late arriving, forcing prime contractors to rely on interim solutions to stay in business.

Responsibility for developing hospital software currently lies with three specialist subcontractors, Cerner in the south of England, IDX in London, and iSoft in the Midlands, the northeast, and east of England. A fourth important supplier is the general practice systems firm Emis, which after an initial estrangement from the national programme has reached an agreement to act as an alternative supplier to practices across England.

At least some of the hospital suppliers are behind schedule developing software procured through the programme. Because of the policy of paying only on delivery—a novelty in public sector information technology projects—this shows up in their public accounts. In January, iSoft warned shareholders that delays to the programme would affect its profits.

Connecting for Health said in a statement: "There has been some system deployment rescheduling because suppliers and their subcontractors have taken longer than anticipated to deliver some software solutions. In the context of a 10 year programme, the impact of this is limited." 6

Delays have local consequences, however. To try to keep the programme on track, local service providers are deploying various interim solutions. In acute trusts, these are little more than basic patient administration systems, lacking the functions of electronic patient records that some hospitals had already installed in line with the 1998 Information for Health strategy. Rather than accepting the proposed interim solution, a handful of trusts needing to replace their existing systems urgently for contractual or technical reasons have chosen to procure new systems outside the programme. The latest example is Northumbria Healthcare.

In at least one case, the deployment of an unsatisfactory interim solution may have serious consequences for public health. In February, Connecting for Health admitted that an interim child health system hastily developed by BT, the provider for London, "did not provide all the necessary reports about the children's immunisation status" and that manual procedures arranged by primary care trusts could mean some parents had "not been correctly advised of their children's immunisation needs"<sup>7</sup>

Although delays in delivery are an embarrassment to a programme that had set much stock on running to timetable, they are not necessarily bad news. They give the programme time to resolve tricky and controversial questions surrounding the content of, and access to, the care records service.

#### Protecting patients

The clinical leaders of Connecting for Health say that the public strongly support electronic health records being shared between professionals; patients are often upset when they discover that sharing is not the norm. This is based on research carried out in 2002, before the national programme took shape. The research made no mention of social care records, beyond revealing that only 23% of people would be willing for their NHS records to be shared with "social care staff."

To comply with data protection law and professional ethical practice, patients need to give informed consent to having their records shared. At the moment, the intention is to achieve this by informing patients of their right to opt out of the care records service (though not of the personal demographics service). A system of "sealed envelopes" is also planned so that patients can control access to specific parts of their record. These and other measures are set out in a care records guarantee. A £5m public information campaign due to begin this summer will inform patients of their rights.

One aim of the campaign will be to minimise the number of people opting out by reassuring patients that the care records service will be secure. Access to the system will be available only to staff issued with a

smartcard, which will leave a clear audit trail and alert privacy officers to unusual requests. In public speeches, Richard Granger, Connecting for Health's chief executive, contrasts these procedures with the common current practice of leaving case notes unattended on reception desks and trolleys, with no record of who has viewed them. The comparison is disingenuous, however. Today, unscrupulous media organisations or private detectives would have to cultivate hundreds of NHS staff to have a good chance of getting access to any specific record. When records are available regardless of geography, they will need to find only one insider open to bribery or coercion. Even if the system guaranteed that the access would be detected, the damage might already have been done.

Although patient consent is the most controversial current issue, the use of universal, shared, electronic health records is likely to pose several challenges to medical practice. One is the need for better record keeping: doctors will have to enter data on the basis that they may be used by complete strangers to make critical decisions and viewed by the patients themselves (eventually, through the MyHealthspace system, to be launched on a revamped public website which will replace the current NHS Direct online). There is no room in this world for informal codes such as the apocryphal "normal for Norfolk."

Serious questions also remain unsettled about what information should go on the record, especially when it comes to a patient's social circumstances or information about third parties such as family members. One certainty is that the lifelong electronic health records created in partnership by doctors, other professions, and patients themselves will look very different from today's case notes.

#### Adapting to change

Four years after its conception, the NHS national programme for information technology still has the flexibility to accommodate changes in direction. A "refresh" of the programme's approach, expected shortly, will be presented largely as a response to the white paper Our Health, Our Care, Our Say, 10 answering criticism that the national programme is poorly aligned with the government's NHS reforms. The refresh is likely to find ways of offering more choice in systems, while retaining the programme's national character. Richard Jeavons, the former health authority chief executive appointed last year to oversee the programme's implementation, says that in the new mixed health economy, connection to the national care records service will be more important than ever. "In the post reform world, it will be one of the few defining features of the NHS, along with treatment free at the point of care.'

The refresh will also need to find ways to inject some excitement into the programme. One possibility would be to create a few exemplar sites by quickly assembling components of electronic health records in the most promising sites. These might best be based on "natural communities" of a trust and general practices, rather than the local service provider boundaries, which were set to create billion pound contract opportunities rather than to reflect NHS data flows.

#### **Summary points**

The NHS information technology programme plans to transform medical records into a single resource shared by everyone involved in the process of care

The programme relies on connecting all care systems to a central record or spine

Delays in developing hospital information systems compliant with the spine have resulted in trusts having to adopt less functional systems

Public confidence in the security of the system will be essential to a useable spine

Four years into its story, it is still too early to predict whether the NHS programme will succeed or fail. The only guide is from history—that pioneers tend to overestimate the speed of technological change but underestimate its long term impact.

Contributors and sources: MC has written on healthcare informatics issues for journals, newspapers, and books for more than

Competing interests: MC carried out a short assignment for the national programme for information technology in 2002 and has also written occasional articles and accepted paid speaking engagements for at least two contractors to the programme, BT and Microsoft.

- 1 Institute of Medicine. The computer based patient record. Washington, DC: IoM. 1997:55.
- Medix. Doctors' views about the national programme for IT. Jan 2006. www.medix-uk.com (accessed 5 Mar 2006).
- Byrne L. Care records. House of Commons Official Report (Hansard): 2006
- Connecting for Health. *Update on recent service issues, 16 Jan 2006.* www.connectingforhealth.nhs.uk/news/update\_service\_issues (accessed
- Anon. Engaging clinicians in IT—one step forward, two back. BMJ
- Connecting for Health. Spending and progress update 2006. www.connectingforhealth.nhs.uk/news/news300106\_spending (accessed 7 Mar 2006).
- Connecting for Health. Response to child health interim application media www.connectingforhealth.nhs.uk/news/child\_health\_systems coverage. (accessed 8 Mar 2006).
- 8 NHS Information Authority. Share with care! People's views on consent and confidentiality of patient information. London: NHSIA, 2002
- NHS. The care record guarantee. London: Connecting for Health, 2005. www.connectingforhealth.nhs.uk/all\_images\_and\_docs/crbb/ crs\_guarantee\_2.pdf (accessed 7 Mar 2006).

  10 Department of Health. Our health, our care, our say. London: DoH, 2006.

#### Endpiece

#### Seeking enlightenment

Those who seek should not stop seeking until they find. When they find, they will be disturbed. When they are disturbed, they will marvel, and will reign all over.

The Gospel of St Thomas

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